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AUTHOR	Raciocot, Lina; Shelley, Lynn
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ABSTRACT

Since 1986, federal law has mandated that states provide appropriate early intervention for children from birth to age three with disability or developmental delay. Current federal legislation has focused on expanding services into natural environments other than the child's home. Natural environments are settings in which the child would be if he or she did not have a disability. In response to these policy changes, this study surveyed 23 parents involved with a New England early intervention center about their child's intervention services. Findings show that parents want services in natural community settings, but also like services in the home and at the intervention center. Parents also report some problems associated with natural environments, such as safety, confidentiality, disruptions, and cost. In addition, parents indicate that they would like children without disability or delay included in their child's play group. Parents have strong opinions about what is best for their child. Clearly, policy changes should not be implemented without understanding the needs and perceptions of the families. The survey is attached. (Contains 4 tables and 20 references.) (Author/SLD)

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Running Head: PARENTAL PERCEPTIONS

Parental Perceptions of Early Intervention:

A Survey of Parents from a New England Early Intervention Center

Paper Presented at the Northeastern Educational Research Association Annual Conference October 2000

Lina Racicot

University of Massachusetts-Amherst

Lynn Shelley

Westfield State College

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Abstract

Since 1986, Public Law 99-457 has mandated participating states to provide appropriate early intervention for children age birth to three with disability or developmental delay. Current federal legislation has focused on expanding services into natural environments other than the child's home. Natural environments are settings the child would be if he or she did not have a disability or delay. In response to these current policy changes, this study surveyed parents involved with a New England early intervention center for their child's early intervention services. Results indicated parents wanted services in natural community settings, but also liked services in the home and at the center. Parents also reported there were some problems associated with natural environments such as safety, confidentiality, disruptions, and cost. In addition, parents indicated they would like children without disability or delay included in their child's playgroup. Parents have strong opinions on what is best for their child. Clearly, policy changes should not be implemented without understanding the needs and perceptions of the families.

Parental Perceptions of Early Intervention

A Survey of Parents from a New England Early Intervention Center

Since 1986, Public Law 99-457 has mandated participating states to provide appropriate early intervention for children age birth to three with disability or developmental delay. Some of the primary goals of early intervention were to understand what families wanted for their children, and how professionals could help them achieve those goals (Bailey, 1991; Bernheimer, Gallimore & Kaufman, 1993). With those goals in mind, parents from a New England early intervention center participated in a survey. In addition to describing the methods and results of the survey, this paper provides a rationale not only for the importance of family involvement, but also for the contemporary issue of natural environments.

Clearly, with early intervention legislation, policy makers intended to endorse an approach centered on family decision-making (Gallager, 1989). In 1997, the Part C amendment to Public Law 99-457 mandated not only a family-centered, but also a least restrictive environment approach to early intervention. In cohesion with the provisions of Part C, the most common location for intervention became the child's home. Current federal legislation focused on expanding services into natural environments other than the child's home.

Natural environments are settings where the child would be if he or she did not have a disability or delay. They include community settings such as day care centers, medical centers, playgrounds, libraries, stores, restaurants, and the YMCA. Recently, including children without disabilities in playgroups at the early intervention center has

been considered a natural setting. In general, natural environments can encompass all integrated community settings (Noonan & McCormick, 1993).

Recent research has indicated natural environments are well accepted among early intervention service providers, and are effective settings for some type of services such as coaching, modeling, parental guidance, and technical assistance (Racicot & Shelley, 1998). However, it remains to be seen if parents agree with these outcomes. Despite the lack of parental input, the state in which the surveyed parents reside has assertively attempted to expand early intervention services into natural environments. Government standards call for a justification statement of why services are *not* being provided in natural environments (House Report 102-198). It is anticipated that all early intervention services in this New England state will be provided solely in natural settings by July 2002 (Advisory Task Force, 1999).

The theoretical rationale for this expansion into natural environments is based on the concept of least restrictive environment, which mainly entails lessening the limitations in the life of a child with disability. With lessened limitations a child may reach potentials that may not otherwise be obtained. Least restrictive environments are defined by Public Law 99-457 as settings for children with disability that are as close as possible to settings of young children without disabilities (Hanson & Lynch, 1995).

This same definition is used to describe natural environment, and encompasses inclusion programs. Integrated programs provide children with disability opportunities to spend time with non-disabled peers (Hanson & Lynch, 1995). Some of the beneficial gains for children with disability participating in inclusion groups include opportunities to develop social, motor, and language skills (Langa & Feinberg, 1996). Although

natural environments have benefited children with disability, it has been questioned whether they should replace the use of the early intervention center. Both natural environments and traditional center based services have made unique contributions to early intervention (Racicot & Shelley, 1998).

For a clearer understanding of the multifaceted issues surrounding early intervention, policy makers must turn to the families involved. Early intervention law was written with the intention of leaving the final decision in the hands of the parents, and recognizes the family as an ultimate source of information (Dockecki & Heflinger, 1989; Gallager, 1989). Without input from the families involved the system fails to reach the family centered provisions of the law.

The theoretical rationale for a family centered conceptualization to early intervention is based on an ecological approach to human development. Bronfenbrenner (1977, 1979) proposed a child's life should be conceptualized as occurring across a series of integrated systems. Within each child's ecological system are integral sub-systems that include a proximal system, such as family, home and school, and larger systems of neighborhood, community, and society.

Young children with disabilities combine a number of these ecological variables to constitute a unique family culture (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Schuck & Bucy, 1997). A framework based on this culture increases family empowerment and opportunities for parents to influence their child's development. The importance of parental involvement in service planning is now recognized in both policy development, and program implementation in early intervention (Whitehead, Jesien, & Ulanski, 1998).

Clearly, there is a strong empirical rationale for services that support family involvement in early intervention. Theoretically, this includes services in natural environments. The question remains, which settings are indeed family-centered? In light of the great diversity found among families, what exactly does a family centered intervention program really mean (Hanson & Lynch, 1995)? This question can only be answered by gaining information directly from the families.

The information obtained from this study helped the New England early intervention center to understand the needs of the families involved. Specifically, the survey allowed the center to recognize where parents wanted services for their child. It also helped clarify which problems were associated with each setting, what services were well suited for the settings, and if parent's wanted children without disabilities included in their child's playgroup. Effective changes and improvement in early intervention policy can only be achieved through considerable research, which must include a collaborative effort between parents and professionals (Noonan & McCormick, 1993).

Methods

Procedure

Seven full time service providers from a New England early intervention center were asked to distribute the survey to parents. They included two educators, two social workers, a speech language pathologist, an occupational therapist, and a physical therapist. Each service provider received five copies of the survey, along with a cover letter explaining the survey. Surveys were placed in their mailboxes at the center.

Service providers distributed surveys to parents and were asked to assure confidentiality to the parents. Two weeks later service providers received another letter

reminding them to return surveys by April 6, 1999. Service providers returned surveys completed by parents to a designated mailbox at the center.

Sample

Twenty-three parents participated in the survey. Each of these parents received services for their delayed or disabled child from a New England early intervention center. Surveys were distributed to parents who received services for their child either at home, the center, in natural environments, or a combination of locations. Some parents who participated in the survey were also a part of the center's parent group.

Instrument

The *Parental Perception Survey* was developed by the author in collaboration with one of the service providers from a New England early intervention center. A version of the survey was piloted. Any confusing terms were revised or eliminated. Parents indicated they did not understand the term "natural environments", therefore it was replaced with the term " community settings". The final survey (see Appendix A) was revised to one page in length, and was designed at a fourth grade reading level.

The survey included five sections of statements. The first section included two statements. For this section parents checked yes or no, depending whether they liked services at the center or in the home. The second section listed community settings, which parents checked if they wanted services for their child at that location. The third section consisted of a list of five statements. For each statement parents checked either center, home or community, depending on which they liked best for each statement. The fourth section included six problem statements. For each of these statements parents checked center, home, community, or a combination of these locations, if they had

experienced problems there. In the last section parents chose whether or not they wanted children without disabilities or delays included in their child's playgroup. Descriptive statistics were computed for all data.

Results

Location Preference

There were a total of twenty-four responses to the two statements in section one. Parents indicated they liked both the home and the center (75%) as locations for early intervention service. Thirteen percent indicated they liked services only in the home. Eight percent indicated they liked only center services. Four percent indicated that they liked services in the home, but did not like services at the center.

Insert Figure 1 Here

When instructed to check which community settings were preferable for early intervention services, there were forty-four responses. The library (21%) was the most common response chosen by the parents. Other responses included daycare (18%), YMCA (18%), park (18%), store (7%), doctor's office (7%), restaurant (7%), welfare office (2%), and other (school) (2%).

Insert Figure 2 Here

Locations Best for Services

In section three, there were twenty-two responses to the statement "playing with other children". Seventy-three percent chose the center as best for this statement. Twenty-seven percent reported community settings were best for playing, while none chose the home. When indicating which location was best for their child to learn from the teacher there were nineteen responses. The center (58%) was the most common

response followed by the home (21%) and community settings (21%). When rating fun for their child there were twenty-two responses. Forty-one percent chose community settings followed by the center (36%), and the home (23%). Out of nineteen responses, parents reported the center (63%) as best for parenting groups followed by community settings (26%) and the home (11%). There were nineteen responses to statement five in section three. Parents indicated the home (58%) was best for their family followed by community settings (26%) and the center (16%).

Insert Figure 3 Here

Location Problems

In the section of problem statements, there were sixteen responses to "safety for my child". This was a problem associated with community settings (81%), followed by the center (13%), and the home (6%). There were nine responses to the problem of transportation. Transportation was a problem for the center (44%). It was also a problem for community settings (33%) and the home (22%). There were seven responses to the problem of confidentiality. This was a problem for community settings (86%) and the home (14%), but not for the center. There were nine responses to the problem of "my other children want to play". This was a problem for all three locations equally, center (33%), home (33%), and community settings (33%). For the problem statement of "other people disturb us" there were five responses. Being disturbed was a problem for community settings (60%) and home (40%). The center was not indicated for this problem. Seven responses indicated cost was a problem for community settings (71%), the center (14%) and the home (14%).

Insert Figure 4 Here

Inclusion

In the final section, when parents were asked whether or not they wanted children without disabilities included in their child's playgroup, there were a total of twenty-two responses. Seventy-seven percent of the respondents indicated yes. Twenty-three percent of the respondents indicated no.

Insert Figure 5 Here

Discussion

Similar to service providers in previous research, parents indicated they liked both the home and the center for early intervention services. Parents also wanted services for their child in various community settings. The library was the most common setting chosen by parents for services in natural environments. Other popular natural environments included day care, the YMCA, and the park.

In addition, parents indicated certain locations were "best" for some type of services. For example, the center was seen as best for playing with other children, learning from the teacher, and parent group. Community settings were seen as best for "fun", and the home was seen as best for the family. The home continues to be the most convenient location for services. However, the center and community were seen as beneficial.

Some problems were associated with the center and community settings. Transportation was a problem associated with the center. Community settings were associated with the problems of safety, confidentiality, disruptions, and cost. Despite some problems, natural community settings have been praised as ideal for social interaction and communication skill building (Noonan & McCormick, 1993).

Although most parents indicated they would like to see children without disabilities included in their child's intervention, there were some parents who did not. Care must be taken that individual needs of the child and family are not superseded by the commitment to the cause of inclusion (Bricker, 1995). It may be that parents of children with disability fear the uncertain effects of inclusion on their children (Richey, Richey & Webb, 1996). To better serve the families, it is of crucial importance to clearly understand why some parents do not want children without disability or delay integrated into their child's playgroup. This is an area that is in need of further exploration.

Conclusion

Legislation has required parental involvement in defining early intervention goals, including the decision of where services should be provided (Saunders, 1995). Although this study gained crucial information in this area, there were some limitations. The primary limitation to this study was the small sample size. Another considerable limitation was the selection of participants by the service providers. Parents may feel indebted to a particular service provider, and may be reluctant to express dissatisfaction (Wesley, Buyesse & Tyndall, 1997). Future research should include a randomly chosen larger sample.

Parents from the New England early intervention center have definite opinions on where services should be provided. According to parents, although the home was the best location for their family, the center and community settings made unique contributions to early intervention. Response to this survey has made it clear that parents feel early intervention centers should not be completely eliminated or replaced by natural settings. Each location has value to the potential development of their child.

Parents know what is best for their child. They should be involved in the decision making for the nature, location and intensity of early intervention (Wesley et al., 1997). Clearly, policy changes should not be implemented without understanding the needs and perceptions of the families. Rather than wait until a program is well established, policy makers could benefit from the ideas and visions of the parents from the onset (Wesley et al., 1997). Policies that will stand the test of time will reflect the family-centered nature of early intervention law, and will be grounded in science and literature (Harbin et al., 1991).

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Figure 1

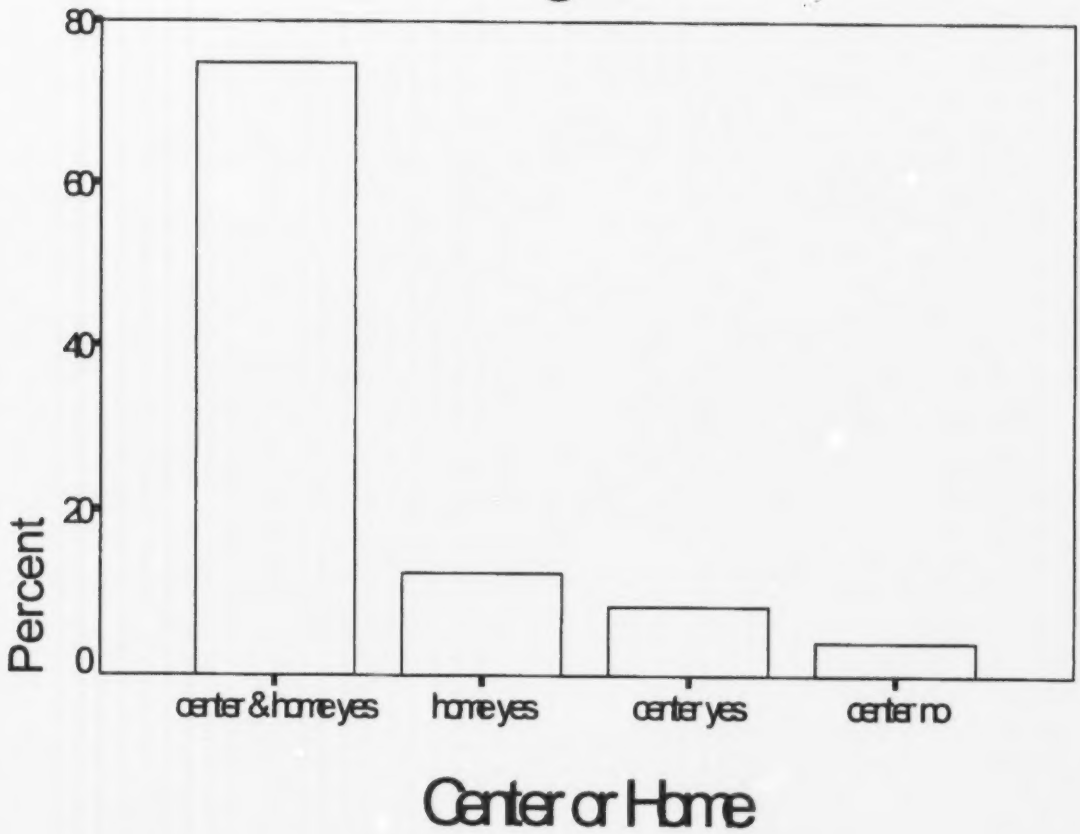

80
60
40
20
0
Percent
center & home yes
home yes
center yes
center no
Center or Home

Figure 2

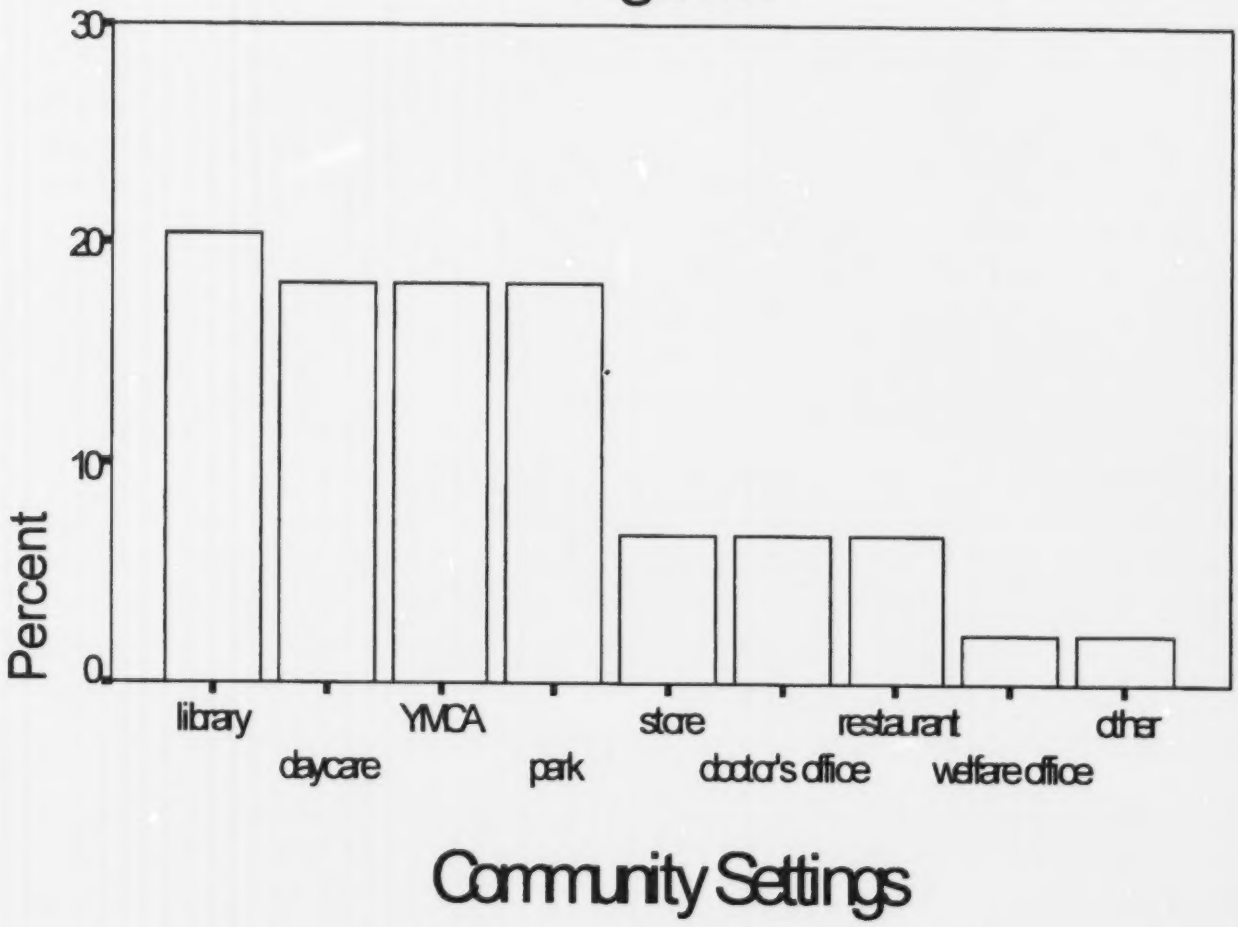
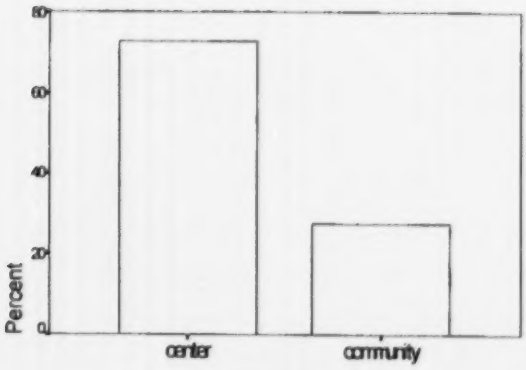
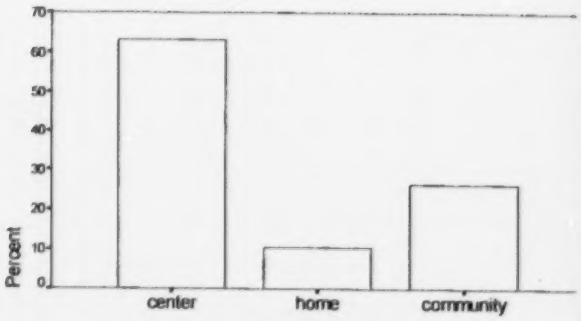

30
20
10
0
Percent
library
daycare
YMCA
park
store
doctor's office
restaurant
welfare office
other
Community Settings

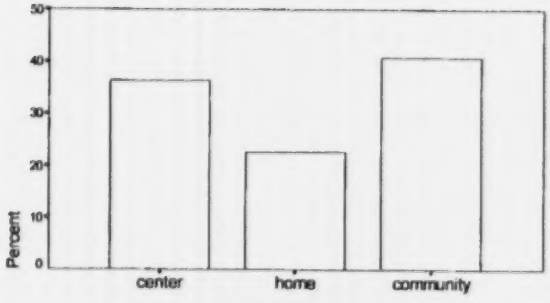
Figure 3



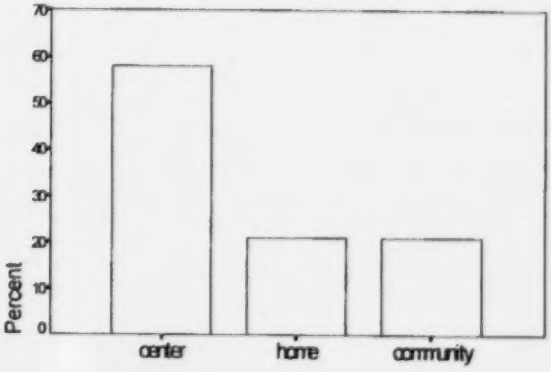
Playing With Other Children



Parent Groups



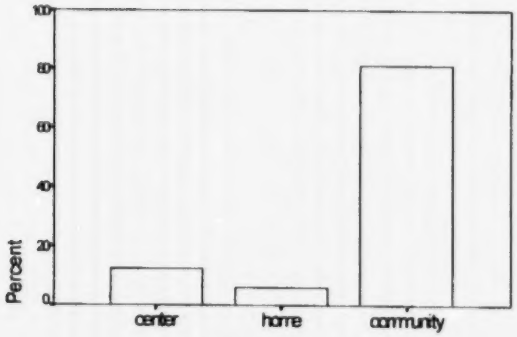
Fun For My Child



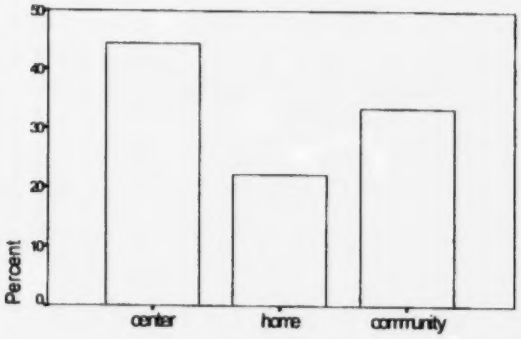
Learning From The Teacher

Best For My Family

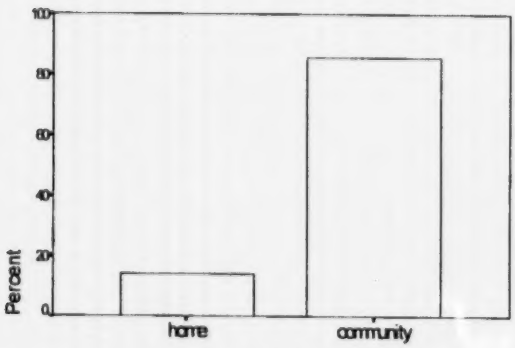
Figure 4



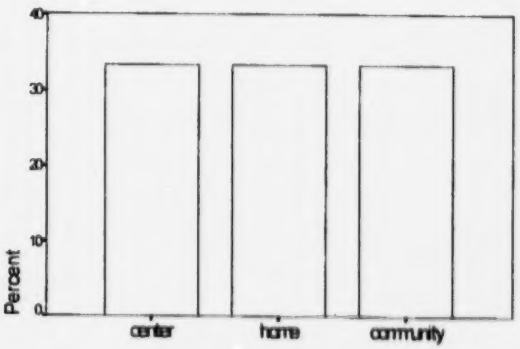
Safety For My Child



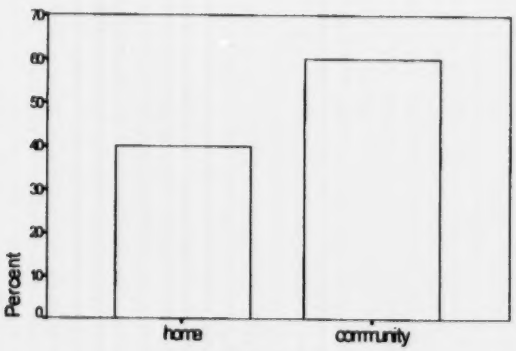
Transportation



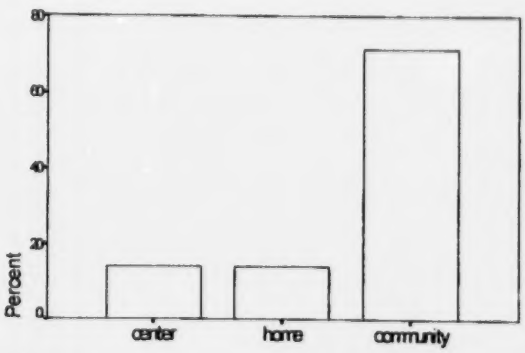
Confidentiality



My Other Children Want To Play

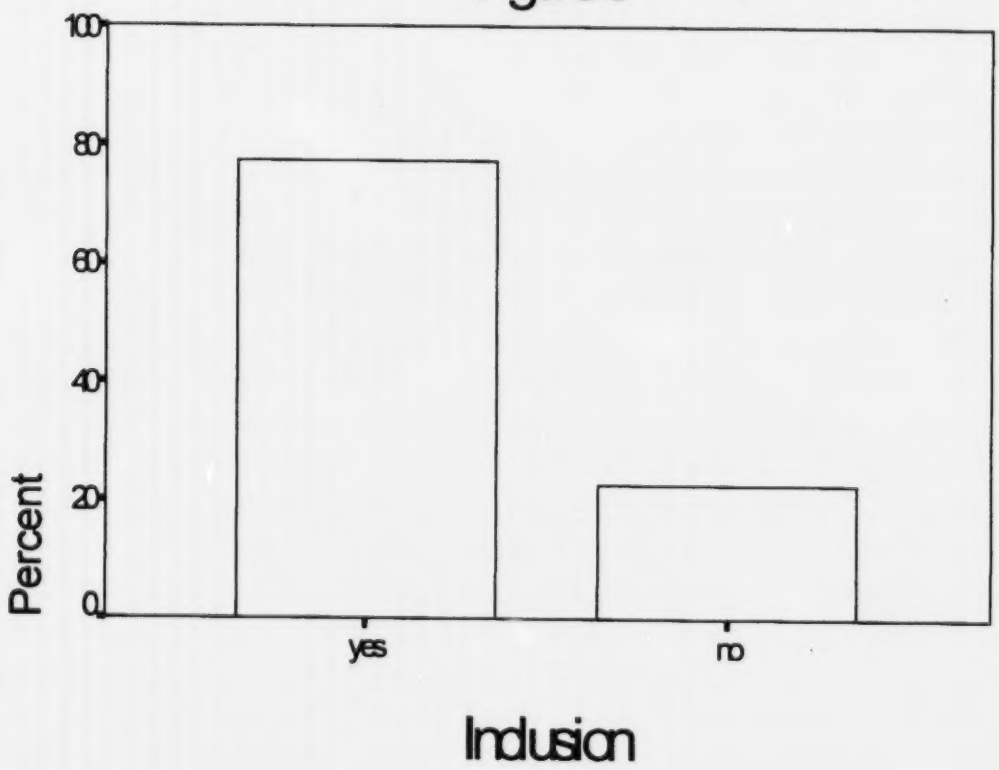


Other People Disturb Us



Cost

Figure 5



Appendix A

Descriptive Statistics for:
Parental Perceptions Survey

Please tell us your opinion on Early Intervention Services for your child. Your ideas are important!

	YES	NO
1. I like services for my child at the center	8%	4%
2. I like services for my child in my home	13%	0%
Both home and the center	75%	0%

****

Community Settings:

2. Check other places where you want services for your child:
(Pick as many as you like)

Library 21% Store 7% YMCA 18% Park 18% Welfare Office 2%

Doctor's 7% Restaurant 7% Day Care 18% Other (school) 2%
(Please List)

****

3. Check one place you like best for each sentence:

	Center	My Home	Community Settings
Playing with other children.....	73%	0%	27%
Learning from the teacher.....	58%	21%	21%
Fun for my child.....	36%	23%	41%
Parent Groups.....	63%	11%	26%
Best for my family.....	16%	58%	26%

****

4. Check where you have these problems:(can be more than one)

	Center	My Home	Community Settings
Safety for my child.....	13%	6%	81%
Transportation.....	44%	22%	33%
Confidentiality.....	0%	14%	86%
My other children want to play....	33%	33%	33%
Other people disturb us.....	0%	40%	60%
Cost.....	14%	14%	71%

****

5. I would like to see children without delays or disabilities included in my child's playgroup

YES	NO
77%	23%

THANK YOU!

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Furcolo Hall
Amherst, MA 01003-3025

Telephone: 413 589-2982 FAX:

E-Mail Address: linaracicot@comcast.net

Date: 10-21-03

(Over)

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